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ABSTRACT

The Individuals with Disabilities Education Act (IDEA) requires the implementation of a comprehensive child find system. This system includes public awareness activities to inform parents, professionals, and the community at large of the availability of early intervention and preschool services, of the importance of identifying children with or at risk for developmental delay and disabilities, and of procedures for referral for evaluation and services. This paper describes strategies used by a variety of health care, early intervention, and preschool service systems for sharing information and collaboratively promoting community child find and public awareness activities. Specific examples of how some projects, states, and communities have implemented these strategies are described and contact information for each example is given. Additional references and resources are also included. (SG)

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HEALTH SERVICES FOR YOUNG CHILDREN UNDER IDEA

FINDING & REFERRING INFANTS & PRESCHOOLERS WITH DEVELOPMENTAL & HEALTH NEEDS

PAPER NO. 2

JUNE 1994

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Health Services for Young Children Under IDEA

Paper No. 2, June 1994

Finding and Referring Infants and Preschoolers With Developmental and Health Needs

Health professionals — working in hospital newborn nurseries or NICUs, public health clinics, or private pediatric and family practices — play an important role in a comprehensive early intervention and preschool child find system. Health personnel often are the first people outside of the child's family to suspect or identify a developmental delay or risk for such a delay and to refer families for an evaluation and services. However, health personnel may not always be aware of the full array of early intervention and preschool services available in their community or state and, therefore, may not be able to inform families of the full range of service options.

Similarly, early intervention and preschool personnel may not always be aware of the options available to families in the health care system. All professionals working with infants, toddlers, and preschoolers and their families must be aware of the services available through the early intervention, preschool, and health care systems, and how to access those services. When child identification and public awareness strategies are developed collaboratively by these systems, access to comprehensive services for families is facilitated.

Implementing a Comprehensive, Coordinated System

To accomplish this referral process, the Individuals with Disabilities Education Act (IDEA) requires the implementation of a comprehensive child find system. This system includes public awareness activities to inform parents, professionals, and the community at large of the availability of early intervention and preschool services, of the importance of identifying children with or at risk for developmental delay and disabilities, and of procedures for referral to evaluation and services. Part B of IDEA requires state education agencies to identify, locate, and evaluate all children with disabilities, from birth through 21 years of age, who need special education and related services. Part H of IDEA requires a comprehensive child find component for children, from birth through 2 years of age, which must be coordinated with all other major state child find efforts. In addition to the state education agency, other state efforts include maternal and child health and Title V programs; Medicaid's Early Periodic Screening, Diagnosis, and Treatment (EPSDT); developmental disabilities; Head Start; and the Supplemental Security Income Program. The child find system also must be coordinated with the efforts of tribes and tribal organizations.

Each state and jurisdictional Part H system also must develop procedures for primary referral sources to use in referring a child to the appropriate public agency and must ensure that referrals are made within 2 days after a child has been identified. Primary referral sources are defined as "hospitals, including prenatal and postnatal care facilities, physicians, parents, day care programs, local educational agencies, public health facilities, other social service agencies, and other health care providers" (see 34 CFR §303.321(d)(3)). The Part H lead agency is required to disseminate information about the basic components of the early intervention system and the availability of early intervention services to primary referral sources, and to determine the extent to which this information

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then is made available to parents through primary referral sources. States also must disseminate information through a central directory of available programs and services for young children with disabilities and their families. Many states provide access to this directory through a toll-free number.

This paper describes ways in which a variety of health care, early intervention, and preschool service systems are sharing information about the services available through each system and collaborating to promote community child find and public awareness activities.

Collaborative Child Find and Public Awareness Activities

To reduce fragmentation and promote collaboration between the health care and the early intervention and preschool service systems, personnel must be kept informed of the services available through each system. Several strategies for collaboration on child find and public awareness activities are listed below. Examples of how some projects, states, and communities have implemented these strategies are described briefly. Contact information for each example is provided at the end of the paper.

THROUGH A VARIETY OF EDUCATIONAL ACTIVITIES, states and communities inform physicians, other health personnel, and consumers about early intervention and preschool services in their communities.

For Example:

- The Medical Home Project in Hawaii has developed a continuing education program for physicians to encourage their involvement on interdisciplinary community-based teams providing services to children with special needs, and seminars for medical office staff on early detection and referral of children with special needs.
- Several state chapters of the American Academy of Pediatrics — including those in Arizona and Nebraska — sponsor a continuing education training series for physicians on the comprehensive care of children with special health care needs.
- The University of Kentucky School of Nursing conducted a 3-year program to prepare nurse leaders from 14 states to train nurses in their communities on their role in early intervention.

COMMUNITY PUBLIC AWARENESS campaigns provide information about early intervention services. Materials are targeted to physicians' offices, local health departments, local hospitals and hospital patient education programs, other health care facilities, parent organizations, state and local resource directories, education and social service agencies, and child care facilities. Hospital and public health nurses and discharge planners play an important role in the referral process for children and families and are a natural link between the health community and early intervention. Including health personnel in the collaborative development of public awareness materials encourages a broader perspective and wider dissemination of the information.

For Example:

- The Portage Project in Wisconsin provides information on early intervention and screening at collaborative functions, such as county health days.
- The Kansas Part H program sends information about early intervention services to pediatricians, family practitioners, local health departments, education and social service agencies, and family support programs.
- American Samoa, Palau, and Guam promote Disability Awareness Week activities on their islands to disseminate information and to build broad support for children ages birth through 5 years. One jurisdiction plans to bring a geneticist to the island for consultations and special clinics during that week.

ONGOING COMMUNICATION BETWEEN the health and early intervention communities, through newsletters, publications of professional organizations, and conference presentations, keeps everyone informed.

For Example:

- *Early Intervention: Quarterly Newsletter of the Illinois Early Childhood Intervention Clearinghouse* is a project of the Illinois Public Health Association.
- Kansas distributes a statewide monthly newsletter, *IT'S NEWS*, to medical and other health personnel, with information about the state's early intervention and preschool programs.
- The Maryland Part H Program has developed a guide for physicians to highlight the importance of earliest identification and referral of children with potential developmental delays, definitions

of eligibility, family-centered care, collaboration among public and private practitioners, and linkage to community resources.

INVOLVING PROFESSIONALS, FAMILIES, AND COMMUNITY MEMBERS from diverse cultural groups can be an effective strategy in reaching underserved populations.

For Example:

- The Redlands Christian Migrant Association in Florida has been involved in a number of community outreach projects to identify migrant children with special needs. The Association employs a variety of strategies, including having staff approach potential clients at community businesses that migrant families frequent (such as convenience stores), identifying community contacts, conducting home visits to interview families, and making follow-up contacts with families to ensure that services are being delivered.
- The Massachusetts early intervention program employs Community Outreach Workers (most often a member of the same culture as that of the families and the community being served) to serve as a bridge between neighborhood support systems and the larger community.

ONGOING PERSONAL CONTACT and communication among health professionals, early intervention providers, and families keep everyone informed and involved. Communication should include follow-up on referrals by evaluation reports and regular progress reports, and by inviting the health personnel's continued participation in the development of the IFSP and the child's and family's early intervention program.

For Example:

- Child Development Resources in Virginia sends notes of appreciation as follow-up to physician referral. Evaluation and progress reports are sent to physicians with an invitation for the physician's participation in a variety of ways, such as attending the IFSP meeting and reviewing the IFSP.

COLLABORATIVE TRAINING is featured by state agencies, universities, and parent and professional organizations.

For Example:

- The Dartmouth Center for Genetics and Child Development, a New Hampshire University Affiliated Program, and the New Hampshire Pediatric Society received funding from the New Hampshire Part H lead agency for a conference retreat involving community-based pediatricians and family practitioners, parents, early intervention professionals, and key state-level administrators. The group identified best practices in providing primary health care to children with special health care needs, especially from the family perspective.
- The Florida Physician Training Project has been developed by state agencies, university personnel, and parent organizations. Training was provided in local communities by parent and physician teams. A training curriculum on developmental screening and family-centered care has been developed for community health care providers.

Contact Information for Examples

American Samoa: Julia Lyons, Part H Coordinator, Department of Health, Government of American Samoa, Pago Pago, AS 96799, (011-684) 633-4929.

Arizona: Raun D. Melmud, M.D., Developmental Pediatrics Associates, 5040 East Shea Boulevard, #166, Scottsdale, AZ 85254, (602)443-0050.

Florida: John Reiss, Florida's Physicians Training Project, Institute for Child Health Policy, 5700 S.W. 34th Street, Suite 323, Gainesville, FL 32608, (904)392-5904; Gyla Wise, Director of Health, Redlands Christian Migrant Association, 219 N. First Street, Immokabee, FL 33934.

Guam: Claire Aglubat (619 Coordinator) and Leilani Nishimura (Part H Coordinator), Division of Special Education, Department of Education, Box DE, Agana, GU 96910, (011-671)647-4400.

Hawaii: Margo Peters, Director, Hawaii Medical Home Project, 1360 South Beretania, Honolulu, HI 96814, (808)536-7702.

Illinois: Early Childhood Intervention Clearinghouse, Illinois Public Health Association, 830 South Spring Street, Springfield, IL 62704, (217)785-1364, in Illinois (800)852-4302.

Kansas: Marnie Campbell, Part H Coordinator, State Department of Health and Environment, Landon State Office Building, 900 S.W. Jackson, 10th Floor, Topeka, KS 66612-1290, (913)296-6135.

Kentucky: Gwendolen Lee, Project Director, Leadership Development for Nurses in Early Intervention, College of Nursing, University of Kentucky, 527 CON/HSLC, 760 Rose Street, Lexington, KY 40536-0232, (606)233-6256.

Massachusetts: Andrea Schuman, Director, Policy and Program Planning, Early Intervention Unit, Department of Public Health, 7th Floor, 150 Tremont Street, Boston, MA 02111, (617)727-5089.

Maryland: Carol Ann Baglin, Director, Maryland Infants and Toddlers Program, One Market Center, Suite 304, 300 West Lexington Street, Box 15, Baltimore, MD 21201, (410)333-8100.

Nebraska: Nebraska Chapter American Academy of Pediatrics, c/o Steve Likes, 7521 Main Street, Suite 103, Omaha, NE 68127, (402)331-0555.

New Hampshire: Donna Schlachman, Acting Coordinator, New Hampshire Infant and Toddler Project, Division of Mental Health & Developmental Services, Department of Health & Human Services, NH Hospital Administration Building, 105 Pleasant Street, Concord, NH 03301, (603)271-5122; W. Carl Cooley, MD, Associate Director for Clinical Services, Clinical Genetics and Child Development Center, Dartmouth-Hitchcock Medical Center, Building 4, Level 5, One Medical Center Drive, Lebanon, NH 03756, (603)850-7884.

Republic of Palau: Elizabeth Watanabe, Part H Coordinator, Special Education, Department of Education, Box 189, Koror, Palau, PW 96940, (011-680)488-2537.

Virginia: Corinne Garland, Project Director, Child Development Resources Inc., P.O. Box 809, Lightfoot, VA 23090-0299, (804)565-0303

Wisconsin: Julia Herwig, Portage Multi-State Outreach Project, CESA 5, 628 East Slifer Street, Portage, WI 53901, (608) 742-8811.

Reference

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Additional Resources

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This is one of a series of papers that discusses the individual components of IDEA and how health services can be fully integrated with early intervention and preschool systems. Each paper is designed as a brief overview that presents practical strategies and examples of successful implementation of those strategies by agencies, organizations, and projects.

The series is written for early intervention and health care personnel from all disciplines who are working at the state and community levels. It is being distributed to the Part H Coordinator, the Section 619 Coordinator, and the ICC Chair in each state and jurisdiction. It is our hope that they will duplicate and disseminate the papers to local early intervention service programs, state and local health departments, hospitals, state and local ICCs, parent organizations, professional organizations, institutions of higher education, advocacy groups, legislators, and other relevant groups.

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